



**PAEDIATRICS**

**A NATIONAL MODEL  
OF CARE FOR PAEDIATRIC  
HEALTHCARE SERVICES  
IN IRELAND  
CHAPTER 39:  
PAEDIATRIC  
PALLIATIVE  
CARE**



Féidhmeannacht na Seirbhíse Sláinte  
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**ROYAL  
COLLEGE OF  
PHYSICIANS  
OF IRELAND**

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## 39.0 INTRODUCTION

*“Palliative care for children and young people with life limiting conditions is an active and total approach to care, from the point of diagnosis or recognition throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement” (ACT & RCPCH 2009)*

Paediatric palliative care (PPC) is care which focuses on the relief of suffering in the child and family by controlling pain and other distressing symptoms, by integrating the psychological and spiritual aspects of care, by offering a support system to allow children and their families to live as active and full a life as possible and by supporting families to help them cope into bereavement. It is an important aspect of medical care for all children with a life limiting condition (LLC) or a life threatening condition or who need end-of-life care. The challenges which must be faced when caring for a child with a LLC are multiple and specific, and differ significantly from those relating to the care of adults. Adolescents requiring palliative care have their own unique needs.

As in adult palliative care services, the aim is to enable every child with a life limiting illness to live as well as possible until he/she dies. End of life care is only a small, although important part of what palliative care is. PPC principles include neither hastening nor postponing death, helping change the focus of care from cure to quality of life (QOL) and weighing the burden versus benefit in all treatments offered. As PPC is a philosophy of care it can happen in any location the child is being cared for.

All healthcare professionals involved in the care of children/young adults living with a LLC need to have an understanding of the core principles of PPC and to be able to adopt them appropriately. Any child with a LLC may have palliative care needs which are usually met by the primary team caring for the child. Therefore not all children with palliative care needs will require specialist palliative care input. The role of the specialist PPC service (SPPC) is to provide expert advice and support in more complex cases for the multidisciplinary teams (MDTs) already caring for these children and also to provide direct support to the child and family as appropriate.

### Life Limiting Conditions

The term life limiting condition refers to any illness for which there is no reasonable hope of cure and where the child is unlikely to survive beyond early adulthood. Many of these conditions cause a progressive deterioration leaving the child increasingly dependent on their family or carers. Such illnesses have been categorised into four categories (Fraser et al, 2012):

#### Group 1

Life-threatening conditions for which curative treatment may be feasible but can fail. Access to palliative care services may be necessary when treatment fails. Children in long-term remission or following successful curative treatment are not included. Examples: cancer, irreversible organ failures of heart, liver, kidney.

#### Group 2

Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Example: cystic fibrosis.

### Group 3

Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples: Batten disease, mucopolysaccharidoses, muscular dystrophy.

### Group 4

Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord insult (ACT & RCPCH 2003).

In Ireland approximately 370 children die each year with LLCs. Of these deaths, 57% occur in the first year of life (DoHC, 2005). In keeping with international experience, it has been more difficult to establish accurate prevalence figures for children with LLCs. Initial estimates of a prevalence rate of 12 children per 10,000 meant that there were approximately 1,400 children living with a life-limiting condition. As predicted, this is believed to be a gross under-estimate based on recent updated UK figures of 32 per 10,000 population, almost three times the previously reported estimates (Fraser et al, 2012). Irish experts have recently recommended review of the national policy based on these higher figures (ref IMJ letter, March 2015). Expert opinion states that approximately half of the children identified with a LLC have palliative care needs at any one time (ACT, 2007).

It is important to note that in contrast to adult palliative care, children with cancer constitute a minority of those referred to palliative care services. Internationally, malignancies constitute only approx 22% of referrals to PPC, with diseases of the nervous system (39.1%), congenital conditions or illnesses originating in the perinatal period (22.1%) or other illnesses (16.7%) making up the majority (Widger et al, 2007). Referrals are likely to increase as the care of children with complex disability improves. Many children with exceptional healthcare needs are surviving for many years and are most appropriately cared for by general paediatricians who are appropriately trained to meet their medical needs. They may have periods of relative stable health interspersed with periods of acute life-threatening illness when palliative care needs may be significant.

## International experience

Internationally, paediatric palliative care has evolved from the specialty of paediatrics rather than adult palliative care. This is in keeping with the United Nations Convention on the Rights of the Child which insists that those working with children should first and foremost be trained in the care of children and young people. Irish palliative care policy also recommends that ideally staff trained in paediatrics should care for children with life-limiting conditions. In the Irish setting the support and input of adult palliative care services will continue to be relied upon to ensure children with LLCs are cared for as close to home as possible and can die at home if that is the wish of them or their families.

The United Kingdom (UK) has been to the forefront in the development of paediatric palliative care services and in the recognition of paediatric palliative medicine as a specialty. In the UK, palliative care services specifically for children have developed, initially from paediatric oncology services, and more recently as palliative care teams in their own right. Together for Short lives (initially called The Association for Children with Life-threatening or Terminal Conditions and their Families or ACT), and the Royal College of Paediatrics and Child Health (RCPCH) in the UK, have been instrumental in producing several key documents regarding the palliative care needs of children. These include key recommendations for the care of children with life-limiting conditions.

As paediatric palliative care (and paediatric palliative medicine) became more established in the UK, the need for widespread paediatric palliative care teams was identified. This resulted in a recommendation in 2007 that there should be subspecialty recognition for paediatric palliative medicine, a paediatric palliative care consultant for each region and a doctor with special interest in the field in each locality (Craft & Killen, 2007). The Combined Curriculum in Paediatric Palliative Medicine (BSPPM & ACHD, 2007) was prepared by the Education Subgroup of the British Society for Paediatric Palliative Medicine (BSPPM) and the Association of Children's Hospice Doctors (ACHD). The aim of the curriculum is to inform the training of all paediatricians who encounter children with life-limiting conditions.

*It defines four levels of competencies which correspond to:*

- Level one: Understands the basic principles of paediatric palliative care
- Level two: Can apply the basic principles of palliative medicine to the care of children specifically. Can recognise reversible causes of symptoms in children, whether with a life-limiting condition or not.
- Level three: Able to manage most common symptoms safely and effectively. Prepared to recognise need for specialist help and access it where necessary.
- Level four: Can manage uncommon symptoms; understands principles in order to develop a logical approach even where there is no evidence basis. Considerable emphasis on leading and developing services within and beyond the local hospice, and on supporting and teaching other professionals involved with children with life-limiting conditions who are not trained in palliative medicine. This level will probably only be seen to be achieved if the doctor has obtained FRCPCH or similar distinction.

## 39.1 CURRENT SERVICE PROVISION

The 'Report of the National Advisory Committee on Palliative Care' (DoHC, 2001), highlighted the need for a review of children's palliative care services. This report was seen as the blueprint for the development of palliative care services in general in Ireland and was adopted as national policy. On foot of the Report of the National Advisory Committee on Palliative Care 'A Palliative Care Needs Assessment for Children' was undertaken and the results published in 2005 (DoHC, 2005). The findings of the needs assessment in Ireland were consistent with those undertaken in other countries.

*The key findings of the Palliative Care Needs Assessment for children were:*

- Inequity in service provision.
- Poor co-ordination of and access to services.
- Home care and community support services need to be developed.
- Accurate data collection on prevalence and mortality was not available
- A 'key worker' was necessary to improve co-ordination of and access to services.
- Further education, training and development of health care professionals was necessary
- Readily available access to locally based respite necessary.
- Planning of the development of services necessary.
- The specific needs of adolescents needed to be considered.
- A broader range of bereavement supports needed to be available.

Following the Needs Assessment, the Department of Health and Children (DoHC) developed the document Palliative Care for Children with Life Limiting Conditions – A National Policy (DoHC, 2010). This policy is the blueprint for how palliative care services for children should be developed and rolled out nationally. This policy sought to address the issues identified in the needs assessment in order to build a responsive service for children and their families.

The policy highlights that a comprehensive children's palliative care service needs to function within a cooperative model with close liaison between general practitioner, consultant paediatrician, nursing services, therapists and the voluntary sector. Children's hospitals and hospitals with paediatric units are central to the ongoing care and management of children with life-limiting conditions. The policy also recommended the appointment of key personnel including a consultant with a special interest in PPC and children's outreach nurses located regionally. The national policy stressed that palliative care services for children should be accessible, equitable, flexible and appropriate and should meet the needs of any child with a life-limiting condition and their family. Children with life-limiting conditions have many of the same requirements as healthy children and need to maintain a normal life for as long as possible. Meeting the play and educational needs of children with LLC was identified as a particular challenge

### **Role of the Specialist Paediatric Palliative Care Team in Crumlin**

Currently (2015), the Specialist Paediatric Palliative Care (SPPC) Team based in Our Lady's Children's Hospital, Crumlin (Crumlin) consists of one consultant paediatrician with a special interest in paediatric palliative medicine, two consultant sessions from adult palliative medicine consultants and 1.5WTE clinical nurse specialists (CNS). There is also a specialist registrar (SpR) in adult palliative medicine and a general practice trainee senior house officer (SHO) who attend twice weekly with the adult palliative medicine consultant.

The team aspires to provide a quality equitable service to all children with life-limiting conditions and their families who have SPC needs as outlined in The National Policy (DoHC, 2010). The paediatric palliative care service in Crumlin is a consult, advisory and supportive service. The team does not take over the care of the child but works in conjunction with the child's primary paediatric team. Referrals are accepted from all specialties (mainly from within Crumlin and the Coombe Women & Infant University Hospitals) and all referrals come from, or are approved by, the child's paediatrician or neonatologist. General practitioner (GP) referrals are seen in consultation with the child's primary paediatrician.

Inpatients in Crumlin and the Coombe Women & Infant's University Hospital are reviewed as soon as is possible. Usually this depends on when the family (+/- child where appropriate) are able and agree to meet with the team. Urgent referrals are reviewed within 24 hours, Monday to Friday. Outpatient referrals may be reviewed as a 'drop-in' or when attending another appointment to reduce the burden on families. An SPPC outpatient clinic commenced in 2015 in Crumlin. The Specialist Paediatric Palliative Care Team accept antenatal referrals from the Coombe Women & Infant's University Hospital. In these cases, potential antenatal referrals are identified at the regular MDT 'Antenatal Diagnosis' meeting. The mother/parents are then referred to meet with the neonatologist and the paediatric palliative care consultant to discuss the diagnosis, prognosis and care of their baby after birth.

The paediatric palliative care consultant has a national remit to advise and support paediatricians in the care of children with LLCs as well as supporting local community palliative care teams as they care for children/young people at end-of-life. This includes telephone advice to paediatricians and regional palliative medicine consultants/home care teams (on a grace and favour basis) 24 hours a day, seven days per week.

*The SPPC service aims to be as equitable as possible regardless of where the child/young person is living:*

- If a child is referred to the SPPC service who is not linked into Crumlin then, as much as is possible, specialist palliative care issues can be managed locally by the child's paediatrician, GP, public health nurse (PHN) and children's out-reach nurse with support and advice via telephone. When appropriate, the locally based adult palliative medicine homecare team +/- 'The Jack & Jill Foundation' are also involved in the child's management/care.
- If the child is attending Crumlin, then the SPPC service are (usually) more directly involved in the management and support of that child's care either when they attend outpatient clinics or are admitted to Crumlin as inpatients. Parents of children that the SPPC are directly involved with also have direct access to the paediatric palliative Care CNS and team (for advice and support) via Crumlin switchboard.
- All children being discharged for 'end-of-Life' care are referred to their local palliative medicine homecare team. This team, in conjunction with the child's paediatrician, children's out-reach nurse, GP, PHN, HSE +/- Laura Lynn hospice at home and 'The Jack & Jill Foundation' manage the child's symptoms and provide support to the child and their family in their home setting. The SPPC team in Crumlin provide telephone support to the local team directly.
- The SPPC team also provide support to all of the healthcare teams caring for children with life-limiting conditions as necessary. Part of the team's role is to help liaise between the multidisciplinary team including the following, the child's general practitioner, primary paediatrician, specialist paediatric team, adult palliative medicine team, local disability service, respite facility, special school, psychology, social work, pastoral care, pharmacy, occupational therapy, physiotherapy, dietitian, play therapy, music therapy plus the paediatric hospice and other voluntary agencies involved in that child's care

## Healthcare Professionals providing Palliative Care Services

### *Consultant with a Special Interest in Paediatric Palliative Medicine*

Following the publication of the national policy (DoHC, 2010), key healthcare professional appointments have been made, including the appointment in May 2011 of a consultant paediatrician with a special interest in paediatric palliative medicine based in Crumlin. This post has received funding from the Irish Hospice Foundation (IHF) for 5 years after which the HSE will take up funding.

*When a child is referred to local specialist palliative care services, the consultant paediatrician with a special interest in paediatric palliative medicine liaises, when necessary with the following:*

- The lead paediatrician responsible for the care of the child and their family
- The consultant in adult palliative medicine within the local specialist palliative care services.

### Adult Based Palliative Care Services

Local adult specialist palliative care services (both hospital based teams and community home care teams) provide support and advice to some children with life-limiting conditions, and their families particularly with regard to complex symptom management and end of life care. This role is especially valued.

### Clinical Nurse Specialists in Paediatric Palliative Medicine

Any specialist service needs the support and clinical experience provided by clinical nurse specialists (CNS) in that area of expertise. Currently there are 1.5WTE CNSs attached to the Specialist Paediatric Palliative Care Team in Crumlin.

*Their role is to:*

- Provide clinical support and advice to patients (where appropriate) and their families as well as to the allied health professionals working with these patients and families
- Aid in the education and empowerment of nursing staff and allied health professionals working with children who have a LLC
- Act as a further resource/support for the children's outreach nurses and the local specialist palliative care CNS

*Paediatric Outreach Nurses for Children with Life Limiting Conditions*

Other key appointments have included eight outreach nurses for children with LLCs. For the initial 3 years, five of these outreach nurse posts have been funded by the Irish Hospice Foundation (IHF) after which the HSE is continuing with funding. The Palliative Care Needs Assessment for Children (DoHC 2005) highlighted the need for co-ordination of services, with improved communication and linking of services and referred to this coordinating role as a 'key worker'. A network of children's outreach nurses to support patients and families in the community was developed to fulfil this role. These posts have helped ensure equity of access to services throughout the country for children with life-limiting conditions and their families, regardless of geographical location.

Initially eight children's Outreach Nurses have been appointed. Evaluation of these initial posts, workload of similar posts, Central Statistics Office (CSO) data on current population by age and figures contained in the Children's Palliative Care Needs Assessment may result in further appointments being necessary. These posts should be allocated to ensure geographical equity of access to this service. As the role of the children's outreach nurse develops further there may be opportunities for some to develop to the higher level of advanced nurse practitioner (ANP).

*The role of the children's outreach nurse for children with LLCs includes:*

- Co-ordination of a service that provides continuity of care and improves quality of life for children with life-limiting conditions and their families
- Planning, implementing, delivering and evaluating care for a caseload of children with life-limiting conditions and their families, in collaboration with local healthcare professionals/carers. This role will apply to both acute and community care settings.
- Facilitation of education and training for health and social care professionals in collaboration with relevant stakeholders.
- Supporting the collection of data in relation to children with LLCs.
- Act as an informed resource and link person for children and family carers and for health and social care professionals involved in the care of children with life-limiting conditions.
- Link with PHNs, Disability Services, Community Children Link Nurses, Adult Specialist Palliative Care Teams and voluntary organisations (e.g. Jack and Jill Foundation Nurses).

The primary focus of the children's outreach nurse is the child and family. The nurse has a clear reporting relationship with the director of nursing (DON) or assistant DON in her/his base location and is also supported in clinical decision making by the child's main paediatrician. Wider support is available from the regional 'Champion' paediatrician, the local adult palliative care team (if involved in the child's care), the consultant paediatrician with a special interest in paediatric palliative medicine, based in Crumlin, and the National Support Network.



Recently a national coordinator of the CONs has been appointed. This role includes providing leadership and managerial support to the CONs and to ensure delivery of a high quality service and compliance with the National Development Committee for Children's Palliative Care.

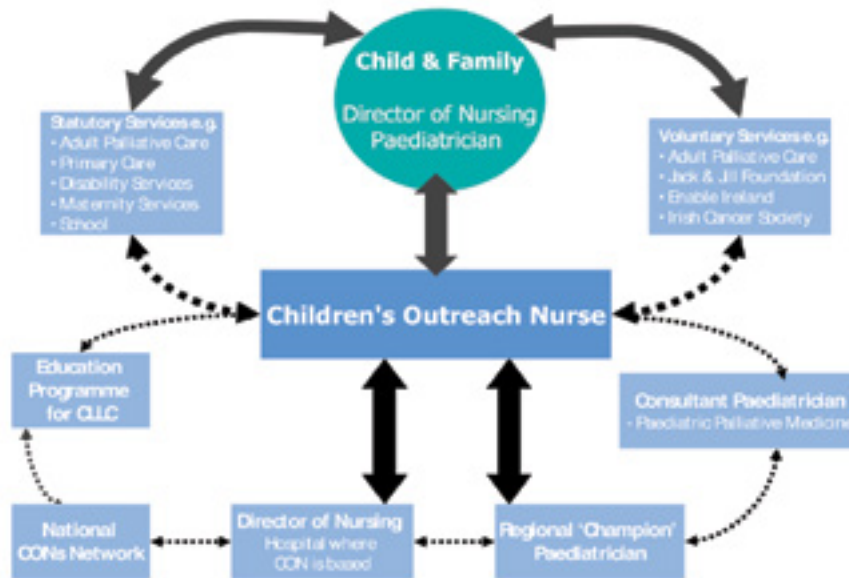


Figure 39.1: Children's outreach nurse

Further detailed information on the role and clinical governance of the children's outreach nurses is outlined in the Children's Outreach Nurses for Children with Life-limiting Conditions; Education and Governance Framework released by the National Development Committee in August 2012 (HSE & IHF, 2012). Appendix 1 displays the map of geographical areas of responsibility for each CON.

### Champion Paediatricians

This role has been developed to support the children's outreach nurses. The role is taken up by paediatricians who have a particular interest in palliative care.

#### The roles of the 'Champion' consultant paediatricians are:

- To champion and support the position and role of the children's outreach nurse in the region
- To strategically develop, in partnership with the nurse manager and children's outreach nurse, the direction of the post
- To act as an advice resource for the children's outreach nurses, and give clinical advice where appropriate
- To champion an interest in children's palliative care within their service
- To introduce/facilitate contact with other paediatricians and health and social care professionals in the acute hospitals, as well as with disability services and voluntary agencies caring for medically fragile children in the region
- To facilitate links and collaboration with the local specialist palliative care teams
- To link with the hospital group clinical director as decided locally
- Support induction and educational programmes in children's palliative care for the local paediatric service
- To support the development of a flexible and responsive local paediatric palliative care service.

### *Multidisciplinary Team Members Providing Palliative Care Services*

In addition to the healthcare professionals described above, the wider multidisciplinary team includes social work, psychology, pastoral care, physiotherapy, occupational therapy, dietetics, play therapy, music therapy, bereavement team. In the community the general practitioner, pharmacist and primary care team play an important role in providing care to a child with palliative care needs. Team work with good communication is essential.

## **39.2 PROPOSED MODEL OF CARE**

Principles and Recommendations for Developing a National Plan for Paediatric Palliative Care

The Palliative Care Needs Assessment for Children (DoHC, 2005) suggested four principles upon which future service developments for children with life-limiting conditions should be based:

1. Inclusiveness

All children regardless of culture, geographical location and age should be able to access appropriate care. All providers should have access to specialist palliative care as required.

2. Partnership

The active participation of all stake holders including the child should be facilitated. Parents should be incorporated as partners in the process of decision-making and in the planning of care.

3. Comprehensiveness

Care should include a focus on psychological, emotional, educational and spiritual needs of a child and his or her family.

4. Flexibility

Care should be adaptable to the individual and changing needs of the child and his or her family. High quality care for children with palliative needs should be provided regardless of location or diagnosis.

*Following on from this, the National Policy (DoHC, 2010) has several recommendations for the future development of children's palliative care services in Ireland. These come under the broad headings of:*

- Implementation of the policy
- Clinical governance
- Children and their parents
- Consultant paediatrician with a special interest in paediatric palliative medicine
- Outreach nurses for children with LLCs
- Acute and maternity hospitals
- Respite services
- Bereavement services
- Education
- Healthcare staff education and research
- National Development Committee for children's palliative care
- Working with voluntary agencies

## Developing the Service

Under the proposed model of care children will continue to access palliative care services from a number of healthcare providers in various settings, see figure X.2. The referral pathway for a child accessing specialist paediatric palliative care services is outlined in Appendix 2.

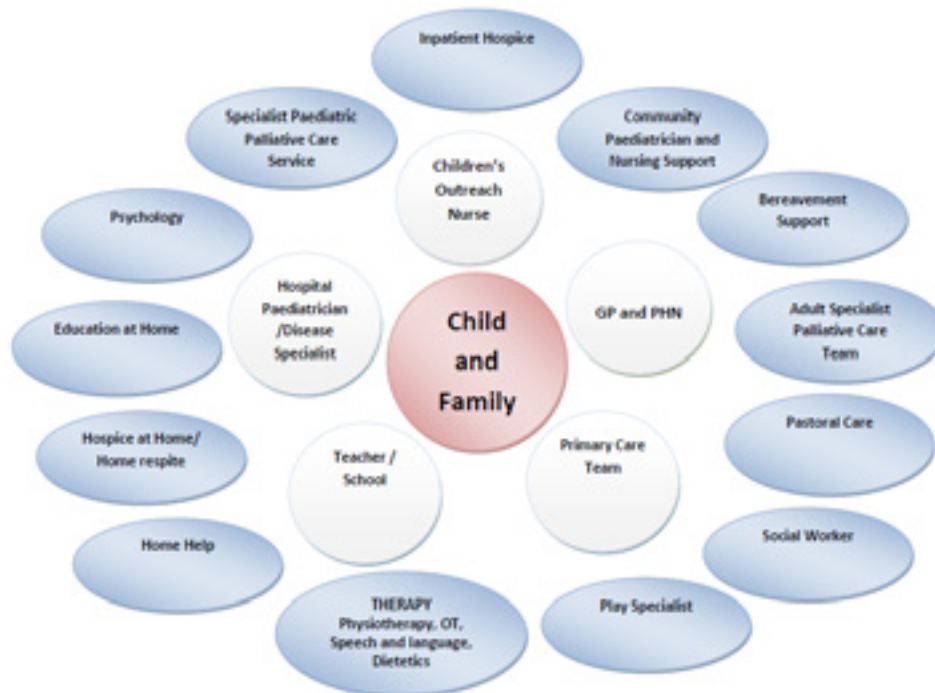


Figure 39.2: Paediatric palliative care service providers

Current paediatric palliative care services are insufficient to meet increased needs. In order to provide a quality, equitable service, development will be required over a number of phases.

### Short term (1 to 4 years)

- Three paediatricians with a special interest in paediatric palliative medicine who work exclusively in children's palliative care are required. One whole time equivalent (WTE) is currently in post in Crumlin, (funding to be formalised). A further two WTEs are required; one for Crumlin and one for Temple Street.
- Two additional CNSs are required, one for Temple Street and one for Crumlin.
- Further resource is required for the provision of the outreach nurse service. There are currently eight outreach nurses with approval for another two WTEs.
- A national lead neonatal nurse for palliative care is required.
- Outpatient clinics which would allow patients to attend for multiple disciplines should be developed.
- The link between paediatric and adult based palliative care services will be required to continue in the future and it is therefore suggested that the clinical governance of this service provision should be supported and further developed.

### Medium term (5 to 7 years)

- A fully resourced specialist paediatric palliative care team is required for the new children's hospital, see 'New Children's Hospital' section below.
- Appointment of general paediatricians with a special interest in paediatric palliative medicine in regional units (Cork, Galway, Limerick)
- Further expansion of the children's outreach nurses for children with life limiting conditions
- Develop perinatal and neonatal palliative care support services
- Support the development of respite-in-the-home services
- Development of a national database of children with life limiting conditions

### Long term (7+ years)

- Maintain and build on the objectives outlined for the medium term
- Funding for palliative care services to be provided by the State
- Paediatric palliative care to be recognised as subspecialty of paediatrics

## New Children's Hospital - Paediatric Palliative Care Team

It is planned that a comprehensive paediatric palliative care team will be developed and that this team will be based in the new children's hospital. Ideally this team will be interdisciplinary with a minimum staff complement of three consultant paediatricians with a special interest in paediatric palliative medicine and their attached medical team (including doctors in training), hospital-based clinical nurse specialists, a social worker, a psychologist and administrative support, and with ready access to the wider range of team members (e.g. occupational therapy, physiotherapy, music therapy, play specialist, dietetics, speech and language therapy). The Children's Palliative Care Team, as at present, will provide a service for children and their families facing any life-limiting condition to ensure the best quality of care, during living, dying and bereavement.

*The National Policy (DoHC, 2010) also states that the Children's Palliative Care Team should be:-*

- Committed to close partnership and joint working with paediatric colleagues, and regional hospitals including the provision of consultation with maternity hospitals, paediatricians based at the tertiary hospital, primary health care teams, and community based services including respite and/or direct care to families on quality of life, symptom management, psychosocial, spiritual care and bereavement follow-up. The emphasis here should be that we aim to provide palliative care at home as much as possible.
- Dedicated to the professional development of health care providers caring for children with life-limiting conditions including a commitment to high quality research, evidence based practice and advocacy on behalf of children and families facing life-limiting conditions.
- Providing clinical leadership, professional development and a mentoring role for the regionally based children's outreach nurses. Each family of a child with life-limiting condition should have contact through the outreach nurse to the Children's Palliative Care Team to help co-ordinate care when necessary.

## An Integrated Service

Robust communication between professionals providing elements of services to children and families across a variety of setting is essential. It is critical for families that the healthcare system operates in a smooth, transparent, joined up manner and that all professionals involved in their child's care are fully apprised of the child's progress at all times. The Together for Sort Lives "The Big Study" 2012 highlighted the concern of parents that their services, and in particular local services, appeared to be delivered in a fragmented, disjointed manner and reported that

communication, collaboration and continuity of staff in whom they could place trust were all elements which should be improved. In developing a model of care for PPC in Ireland, integrated care pathways which include communication standards between tertiary PPC, the local paediatric champion, children's outreach nurses, GPs, local disability teams, local palliative adult service (where required), and other healthcare providers are required to ensure that communication happens in a standardised manner, in a timely fashion with the relevant information and with appropriate frequency.

## 39.3 REQUIREMENTS FOR SUCCESSFUL IMPLEMENTATION OF MODEL OF CARE

### Staffing

Critical to the development of a comprehensive PPC service nationally is the development of expertise in the area. The availability of specialist staff is essential so investment in human resources is essential. A recent article in the leading journal "Paediatrics" makes recommendations on the future development of children's palliative care and hospice services in the United States. In it the American Academy of Paediatrics (AAP) state that "All hospitals and large health organisations that frequently provide care to children with LLCs and routinely provide end of life care should have dedicated interdisciplinary specialty PPC teams" (AAP 2013).

The current consultant paediatrician post needs to be recognised as critical to the development of services and its funding secured. Currently the consultant and outreach nurse programme are being funded primarily by the Irish Hospice Foundation. Of the 2.5 million euro invested in the programme, 85% is being provided by the charity. This responsibility needs to be taken over by the HSE after 5 years as per previous negotiations.

There needs to be further expansion of consultant posts specialising in children's palliative medicine. It is now known that for every 10,000 children attending hospital, 40 have LLCs, challenging the myth that these conditions are rare. It is now recommended that given the evidence of much higher prevalence rates of LLCs the number of children's palliative care consultants should be in proportion with the number of adult palliative care consultants i.e. about 1:4 (Hain, 2013). There is an immediate need for a second post to support the consultant based in Crumlin. Such a post should also be based in Dublin to support the other children's hospitals and with links to local maternity services. Ultimately these would merge as one team at the new children's hospital along with a third consultant post. Links with maternity hospitals are important given the high prevalence of deaths in the neonatal period (ESRI, 2012).

The appointment of consultant paediatricians who have a special interest in paediatric palliative medicine throughout Ireland would allow children with LLCs to be cared for as close to home as possible. This could be incorporated into the development of general paediatrics nationally.

Paediatric palliative medicine needs to be recognized in Ireland as a sub-specialty of paediatrics and as a training post funded to incorporate NCHD training posts. This is essential for the development of the specialty.

With the increase in referrals, there needs to be appropriate development of the supporting team in Crumlin to include increased specialist CNS support and as well as the recommended social worker and secretarial support (DoHC, 2010). Increased CNS support in the PPC team is necessary following the increased workload with the appointment of the consultant. The team needs to be embedded in the new children's hospital when it comes on stream.

Table 39.1: Staffing required for new children's hospital

Staff Category	Current (WTE)	Proposed (WTE)
Consultant	1.2	3.2
SpR Paediatrics	0	1
SpR Palliative Medicine	0.2	0.2
Registrar Paediatrics	0	1
SHO Paediatrics	0	1
Clinical nurse specialist	1.5	4.5
Psychologist	0	1
Social worker	0	1
Administrative support	0.11	1

Access required from: dietetics, physiotherapy, occupational therapy, play specialists

Support required from bereavement coordinator

Further expansion of the outreach nursing programme would also help ensure children live and die well. These posts are a significant support to children and families at home. By providing that vital support, and in fulfilling the key worker role for families, these nurses can help keep children at home in many cases and out of the acute hospital services. A single nurse working regionally however is not sustainable and the programme will need to be expanded.

Palliative care is delivered by a range of disciplines therefore children need access to all support services if they are to die well. This includes access to psychology services when necessary and medical social work and counselling services for all families. Psychologists, when available, play a key role in helping children and families cope with life limiting illnesses. They help with difficult conversations about death and dying, promote coping mechanisms appropriate for the child, manage anxiety etc as well as offering professional support to families. At present psychology services are limited, particularly in the community.

Healthcare staff support for those working in this difficult area is crucial to the well being and continued ability of staff to meet the needs of families and children. This is particularly true for those who provide essential care on an infrequent basis such as the adult home care teams. This work is physically and emotionally very demanding. Consultants can offer support to other health care professionals on an informal basis but the need for formal support in some cases needs to be recognised.

### Infrastructure

Most families wish to care for their children at home. However for some families this may not be possible due to the specific care needs of the child or other practical barriers. Only 11% of children with non cancer LLCs died at home as reported in the needs assessment (DoHC, 2005). This is in contrast to 67% of children with cancer. This is in part due to the greater physical needs of these children with non-cancer LLCs over a more prolonged period of time. In order to address this inequity there needs to be increased practical support for families in the community in terms of respite in the home, easier access to equipment, medical cards etc. This is particularly true at the end of life when the need is often greatest.

There is a heavy dependence on voluntary services such as the Jack & Jill Foundation and the Irish Cancer Society to provide nursing support. These services are not available to all children with LLCs. Increased nursing support

when necessary for children being discharged home for end of life care would facilitate discharge. Currently all children can be referred to local community based adult palliative care teams who provide an excellent service. This is, however, advisory support and not the “hands on” nursing support that some families need. Children and families (both those with cancer and non cancer LLCs) who choose to end their lives in their home environment must be supported through the provision of timely home care packages. These HCPs should include nursing support, additional support from other healthcare professionals within the MDT as deemed appropriate plus provision of specialized equipment in a timely manner.

It needs to be acknowledged, however, that not all families choose home as a desired place of care particularly at the end of life. Hospital may be a more appropriate choice for many as a result of the complexity of some medical conditions requiring intensive ongoing medical input or as a result of complex psychosocial issues, lack of family support or cultural issues. In these situations children must have their palliative care needs met by the hospital-based teams with specialist support when necessary. Improved support to children with LLC in hospital would greatly help in improving how children live and die in Ireland. Current facilities are often cramped and challenging particularly when trying to deliver high quality end-of-life care. It is expected that these limitations will be addressed in the new children’s hospital. National policy states that “Hospitals should provide an appropriate environment for children with palliative care needs. This includes physical environment and professional environment such as staff education and training” (DoHC, 2010).

### Education and Training

Education and up-skilling of existing staff working with life-limited children is essential. Those institutions which care for very ill and fragile children, such as respite facilities and children’s hospices, need to ensure staff have the skills to deliver specialist care when necessary. Ongoing training and education needs to be undertaken and evaluated for effectiveness. Although training is available it can be difficult for staff to access it in the current climate and this needs to be addressed.

A sub-group of the National Development Committee for Children’s Palliative Care has been formed entitled ‘Education in Children’s Palliative Care’. This group is tasked with mapping current training for all health care professionals in children’s palliative care in Ireland and also identifying areas where education needs to be developed and expanded.

*Education and training programmes currently in place in Ireland include the following:*

- Level A and Level B training (CCNE based in Crumlin)
- Clinical workshops (LauraLynn Children’s Hospice)
- 3rd level under- and postgraduate modular studies (NUIG and UCD)

In the UK Paediatric Palliative Medicine is fully recognised as a sub-specialty and there is a curriculum in paediatric palliative medicine (BSPPM & ACHD, 2007). There are several specialist registrar training programmes available. Paediatric palliative medicine needs to be developed in a similar way in the Ireland.

Current training for the children’s outreach nurses for Children with LLCs is outlined in the detailed Governance framework (HSE & IHF, 2012).

*There are several international conferences where it is possible to pursue continuing medical education.*

*These include:*

- The Association of Paediatric Palliative Medicine, APPM, study days (annually, London, UK)
- The Cardiff Paediatric Palliative Care Congress (biannually, Cardiff, UK)
- The European Congress on Paediatric Palliative Care (biannually, Rome, Italy)
- The International Congress on Palliative Care (biannually, Montreal, Canada)

## 39.4 PROGRAMME METRICS AND EVALUATION

Minimum dataset information is sent monthly to the HSE by the Specialist Paediatric Palliative Care Team in Crumlin and also by the children's outreach nurses for children with LLCs.

*The following should also be considered:*

- Establish a database for collecting baseline data on children with life limiting conditions
- Development of integrated care pathways which deal specifically with the standards of communication required between the teams/professionals providing care to these children and families along their care journey
- MDT research into the experience of children and families with LLC in Ireland pre and post implementation of the model

## 39.5 GOVERNANCE

As part of the recommendations by the national policy (DoHC, 2010), a National Development Committee was established in 2011. This committee has the remit of developing children's palliative care as per the national policy. The committee is chaired by the General Manager in Palliative Care within the HSE and there are agreed terms of reference. Annual reports are sent to the Department of Health.

*There are several sub-groups to this committee;*

- National and Regional Networks Committee
- Education in Children's Palliative Care Committee
- Dataset Committee (no longer in existence MDS ongoing)
- Communications Committee
- Respite and Home Care Committee (no longer in existence as the Needs Assessment for Respite Services for Children with Life Limiting Conditions and their Families in Ireland (IHF, LauraLynn, HSE; 2013) has been published)

The paediatric palliative care National Development Committee liaises closely with the National Clinical Programmes for Palliative Care and Paediatrics and Neonatology.



## 39.6 KEY RECOMMENDATIONS

- Increase the paediatric palliative care staffing levels in order to provide a safe, accessible and effective service.
- Establish a database for collecting baseline data on children with life limiting conditions
- Enhance education and training of all staff working with children with life limiting conditions
- Develop integrated care pathways for neonatal and paediatric palliative care
- Enhance discharge planning
- Promote research in paediatric palliative care
- Enhance collaboration between the statutory and voluntary sector

## 39.6 ABBREVIATIONS AND ACRONYMS

AAP	American Academy of Paediatrics
ACT	Association for Children with Life-threatening or Terminal Conditions and their Families
ANP	Advanced nurse practitioner
ACHD	Association of Children's Hospice Doctors
BSPPM	British Society for Paediatric Palliative Medicine
CCNE	Centre for Children's Nurse Education
CNS	Clinical nurse specialist
CON	Children's outreach nurse
CSO	Central Statistics Office
DoHC	Department of Health and Children
DON	Director of nursing
ESRI	Economic and Social Research Institute
FRCPCH	Fellow of Royal College of Paediatrics and Child Health
GP	General practitioner
HCP	Home care package
HSE	Health Service Executive
IHF	Irish Hospice Foundation
LLC	Life limiting condition
MDT	Multidisciplinary team
NUIG	National University of Ireland, Galway
PHN	Public health nurse
PPC	Paediatric palliative care
QOL	Quality of life
RCPCH	Royal College of Paediatrics and Child Health
SHO	Senior house officer
SPPC	Specialist paediatric palliative care
SpR	Specialist registrar
UCD	University College Dublin
UK	United Kingdom
WTE	Whole time equivalent

## 39.7 REFERENCES

Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) (2007) The Transition Care Pathway

Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) (2004) Integrated Multi-Agency Care Pathways for Children with Life-threatening and Life-limiting Conditions

Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) and the Royal College of Paediatrics and Child Health (RCPCH) (2003) A Guide to the Development of Children's Palliative Care Services. Bristol: ACT and London: RCPCH, UK.

Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) and the Royal College of Paediatrics and Child Health (RCPCH) (2004) A framework for the development of integrated multiagency care pathways for children with life-threatening and life limiting conditions. Bristol, UK.

Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) (2007) Palliative Care Statistics for Children and Young Adults. Bristol, UK

Association for Children with Life-threatening or Terminal Conditions and their Families, National Council for Hospice and Specialist Palliative Care Services, Scottish Partnership Agency for Palliative and Cancer Care (SPAPCC) (2001). Palliative Care for Young People Aged 13-24. Bristol, ACT and Edinburgh, SPAPCC, UK

Association for Children with Life-threatening or Terminal Conditions and their Families and Royal College of Paediatrics and Child Health (1997) ACT and the RCPCH (1997) A Guide to the development of children's palliative care services. Bristol: ACT and London: RCPCH

Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) and the Royal College of Paediatrics and Child Health (RCPCH) (2003) The ACT Charter. Bristol, UK.

Association of Children's Hospices (2005) The Children's Hospice Service Toolkit. So you're thinking of setting up a children's hospice service – a guide to what you should know. Association of Children's Hospices: UK.

British Association of Perinatal Medicine (2010) Palliative Care (Supportive and End of Life Care), A Framework for Clinical Practice in Perinatal Medicine. Report of the Working Group

Centre for the Advancement of Health (2004) Report on bereavement and grief research. *Death Studies*, 28 (6), p.489-575 (special issue).

Central Statistics Office (2007) Data on population by age. Available at: [www.cso.ie](http://www.cso.ie)

Craft, A., Killen, S. (2007) Palliative Care Services for Children and Young People in England. Department of Health UK. Available at: [www.dh.gov.uk/publications](http://www.dh.gov.uk/publications)

Curriculum in Paediatric Palliative Medicine (2007) Education Subgroups of the British Society for Paediatric Palliative Medicine and The Association of Children's Hospice Doctor

Department of Health and Children (2001) Report of the National Advisory Committee on Palliative Care. Dublin: Stationery Office.

Department of Health and Children and the Irish Hospice Foundation (2005) A Palliative Care Needs Assessment for Children. Dublin: Stationery Office.

Department of Health (2008) Better Care: Better Lives. Improving outcomes and experiences for children, young people and their families living with life-limiting and life threatening conditions. Available at: [www.dh.gov.uk/publications](http://www.dh.gov.uk/publications).

Department of Health and Children (2008) Building a culture of patient safety. Report of the Commission on Patient Safety and Quality Assurance. Dublin: Stationery Office.

Department of Health and Children (2010) Palliative Care for Children with Life-limiting Conditions in Ireland – a National Policy. Dublin: Stationery Office.

De Vlieger, M., Gorschs, N., Larkin, P. and Porchet, F. (2004) A curriculum for the development of Palliative Nurse Education in Europe. European Association for Palliative Care, Milan, Italy.

Economic and Social Research Institute (ESRI) (2012) Perinatal Statistics Report 2011. Available at: <http://www.esri.ie/pubs/SUSTAT46.pdf>  
Date accessed 26/10/15

Fraser, L. et al (2012) Rising National Prevalence of Life-Limiting Conditions in Children in England, *Pediatrics*; 129; e923;

IMPACT: Standards for Paediatric Palliative Care in Europe (2007) *European Journal of Palliative Care*, 14(3): p.109-114

Irish Hospice Foundation (2012) Children's Outreach Nurses for Children with Life-limiting Conditions. Education and Governance Framework. Dublin: IHF

McNamara-Goodger, K., (2009) A neonatal pathway for babies with palliative care needs. ACT (Action for Children's Palliative Care). Bristol.

National Development Committee for Children's Palliative Care HSE and IHF (2012) Children's Outreach Nurses for Children with Life-limiting Conditions; Education and Governance Framework

Royal College of Paediatrics and Child Health and Chelsea & Westminster Hospital NHS Foundation Trust (2014) Practical guidance for the management of palliative care on neonatal units. 1st Edition

The Irish Hospice Foundation and LauraLynn Children's Hospice (2013) Respite Services for Children with Life Limiting Conditions and their Families – A National Needs Assessment

Together for Sort Lives "The Big Study" (2012)

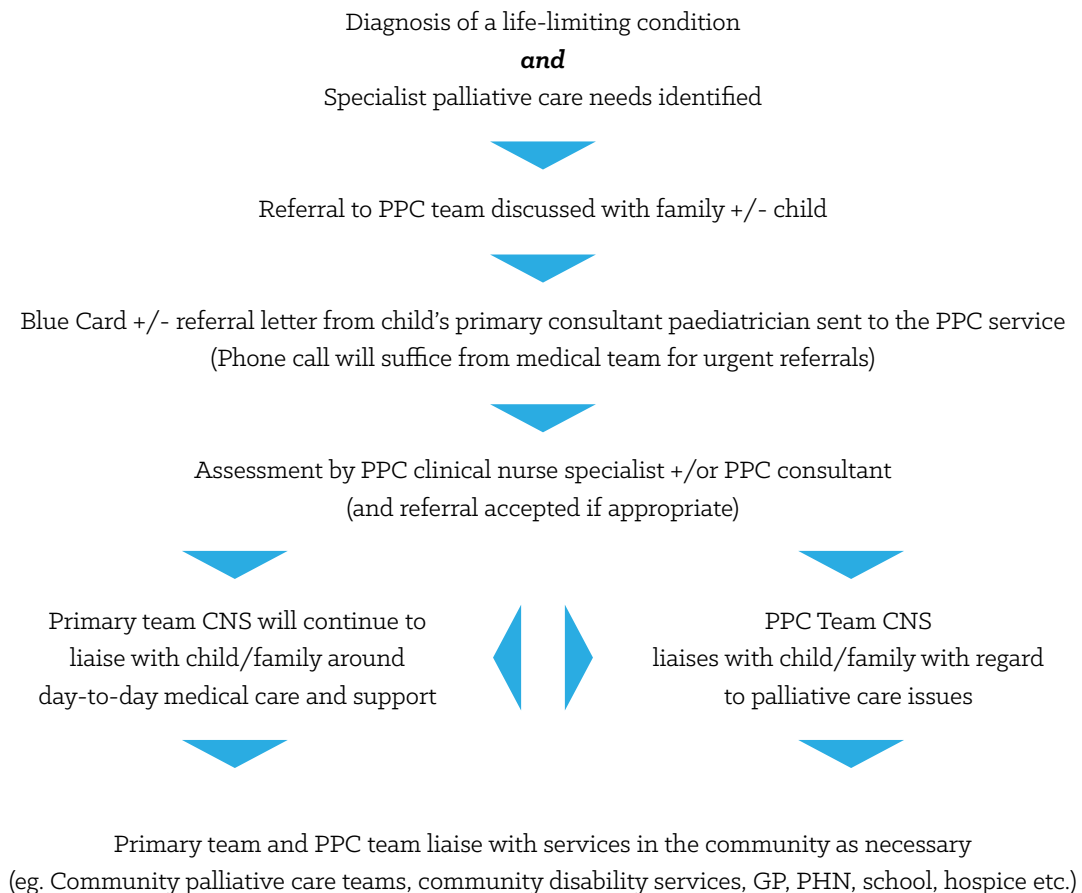
Widger, K. et al. (2007) Pediatric Patients Receiving Palliative Care in Canada: Results of a Multicenter Review. *Arch Pediatr Adolesc Med*, 161, p.597-602

## 39.8 APPENDICES

### Appendix 1 Map of Geographical Area of Responsibility for each Children's Outreach Nurse



## Appendix 2 Referral Pathway to Specialist Paediatric Palliative Care (PPC) Services



### *Which children may require specialist paediatric palliative care (PPC) alongside (or instead of) life-prolonging treatments?*

- 1) Those with a life-limiting or life-threatening condition;
  - a. Ask yourself "Would I be surprised if this child were to die within 1 year?"
  - b. Children who are unlikely to survive into adulthood.
  - c. Children where there is a 'Resuscitation Treatment Agreement' being discussed or is already in place.
  
- 2) Children who fall in the ACT/RCPCH 2003 Criteria ;
  - a. Category 1: Life-Threatening Conditions for which curative treatment may be feasible but can fail. Where access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services (eg. Cancer, Irreversible organ failure of heart, liver, kidney)
  - b. Category 2: Conditions where premature death is inevitable, where there may be prolonged periods of intensive treatment aimed at prolonging life and allowing participation in normal activities (eg. Cystic Fibrosis, Duchenne Muscular Dystrophy)
  - c. Category 3: Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years (eg. Batten Disease, certain metabolic diseases)

- d. Category 4: Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death (eg. Severe Cerebral Palsy, multiple disabilities such as following a brain or spinal cord injury, complex health care needs and a high risk of an unpredictable life-threatening event or episode)

#### *Suggested reasons for involvement of the PPC Team*

- Complex pain +/- Other Symptom management
- End of Life Care (including 'Terminal care')
- Discharge planning, (Including, if necessary, linking in with Community Specialist Palliative Care Team, GP, PHN, Community services etc)
- Assistance with Co-ordination of care.
- Complex issues around Ethics +/- Consent requiring additional supports and information.
- Psychosocial support.
- Bereavement support.
- Education and training

### **Appendix 3 Core Recommendations for Children with Life-Threatening or Terminal Conditions and their Families (ACT)**

#### *Every child and family should expect to:*

1. Receive a flexible service according to a care plan, which is based on individual assessment of their needs, with reviews at appropriate intervals. Children and families should be included in the process of care planning.
2. Be provided with appropriate and timely information.
3. Have their own named key worker to co-ordinate their holistic care and provide access to appropriate professionals across the network.
4. Have access to a local paediatrician in their home area and have access to a local interdisciplinary children's palliative care team with knowledge about the whole range of relevant services.
5. Be in the care of an identified lead consultant paediatrician expert in the child's condition.
6. Be supported in the day-by-day management of their child's physical and emotional symptoms and to have access to 24-hour care in the terminal stages.
7. Receive help in meeting the needs of parents and siblings, both during the child's illness and during death and bereavement.
8. Be offered a range of regular and reliable respite, both in the home and away from home and over varying periods of time. This should include nursing care and symptom management.
9. Have available appropriate supplies of medications, oxygen and specialised feeds and have all disposable items such as feeding tubes, suction catheters and stoma products supplied regularly, efficiently and preferably through a single source.
10. Have access to housing adaptations and specialist equipment for use at home and school, in an efficient and timely manner without recourse to several agencies.
11. Be given assistance in order to access benefits, grants and other financial help.